# Ethical Issues in EoL Care and LTC Support

In whose interest do we provide care?

# Nightingale Reforms

- “To teach the rules of health.....”
    - It has been suggested that nursing was popular in the 19th century because it protected a male, middle class patriarchal society from ‘ugliness’

# Is nursing oppressive?

- Do we impose care upon people?
- Do we coerce?
- Are we 100% participatory?
- Do we label people if they do not comply?
- Do we support difficult/unpopular choices?
- DO we support risk taking behaviour?
- What is our threshold of tolerance?

# To Case Manage

- “The aim of disease management is to take a more proactive approach to managing a disease in order to improve the likelihood of favourably altering it’s natural history. It is a comprehensive and integrated approach. The outcomes include improving quality of care and thus quality of life for the individual and reducing the cost of management of each individual “

  - Plocher (1996)

- Deontological theory
- Considers what one must do based on duties and obligations

- Teleological theory
- Considers outcomes of moral acts
- E.g. consequentialism, utilitarianism

- Virtue ethics

- Focuses on the  character of the decision maker (the agent) – there are no general rules or duties , the complexities of life defy such rules. Virtuous individuals will make good decisions by applying practical wisdom (phronesis)

# Think of your case

- What part of your care was ‘virtuous’?
- What part was based upon obligation or duty
- What part was ‘utilitarian’?

# To Case Manage....Is a utilitarian tool?

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  - Plocher (1996)

# Does utilitarianism lead to oppression?

- Need nursing be a tool for social control?
- Impose or coerce patients
- Euthanasia becomes  an expectation

# Some considerations when providing care

"Given their expectation on reducing utilisation and costs, Managed Care Organisations are at risk of excluding high-cost patients and compromising the quality of care"

Robinson and Steiner (1998), debating USA healthcare

# Vulnerable adults

"Any one aged 18 and over who is dependent on family members, their social network, professionals or volunteers, as a result of a special need arising from the aging process, physical or mental impairment. It is the level of dependency in respect of the meeting of basic needs that renders these adults particularly vulnerable."

DH (2000)

# Vulnerable people

- Poor
- Homeless
- Chronically ill and disabled
- Abusing families
- Pregnant adolescents and their infants
- Frail elderly
- Immigrants and refugees
- Mentally ill

Rogers, (1997)

- Women?

# Vulnerable populations

"..groups of people made vulnerable by their financial circumstances or place of residence; health, age, or ability to communicate effectively [and] personal characteristics such as race, ethnicity and sex."

US Agency for health care policy and research (1998)

# Vulnerable Groups

- Working class
- Ethnic minority groups
- Marginalised groups
  - Travellers
  - Jewish
  - Irish
  - Women exploited through prostitution
  - Disabled
  - Black
  - Lesbians/gay
  - Older people
  - Children and young people

Leeds Inter-agency project's adaptation of Duluth's model

# Avoid Social Labelling

- Ethnocentricity

*"Tendency to evaluate other ethnic groups against our own"*

Gerrish (1999)

- Labelling theory/process
  - Label or name
  - Oversimplify or stereotype past or future
  - Attach or stigmatise
  - Discredit or exclude

Becker (1965)

# Our intention when case finding

- This complexity is the challenge in nursing
- Our *'Raison d'être'* as nurses is human vulnerability
- Cultural competence and sensitivity

# Anti-oppressive practice

- share the values of equity, inclusion, empowerment, and community.
- link the thoughts, feelings, and behaviours of individuals to material, social, and political conditions.
- link personal troubles and public issues.
- see power and resources as unequally distributed, leading to personal and institutional relationships of oppression and domination.
- encourage, support, and ‘centre’ the knowledge and perspectives of those who have been marginalized and incorporate these perspectives into policy and practice.
- articulate the multiple and intersecting bases of oppression and domination while not denying the unique impact of various oppressive constructs.
- conceive of social work as a social institution with the potential to either contribute to, or to transform, the oppressive social relations which govern the lives of many people.
- support the transformative potential of social work through work with diverse individuals, groups, and communities.
- have a vision of an egalitarian future.

# Summary of key ethical theories

- http://www.ukcen.net/index.php/education_resources/support_guide/section_c_ethical_frameworks

(UK clinical ethics network)

# In whose interest do we provide care? Observations from Cystic Fibrosis care

- **Transition from paediatric to adult care:** changing relations between person with CF, parent and health professionals. Who is in control and whose choices are they? Resources allocated? Managing confidentiality?
- **Professional responses to patient choice:** care pathways and individual choice
- **Genetic testing**
- **Obligations to disclose health status to employers, education providers, insurance companies**
- **Planning ahead:** level of respiratory support, transplantation, advance planning

- **Debbie Purdy**

- My name is Debbie Purdy and I live in Bradford with my husband Omar. I was diagnosed with Primary Progressive Multiple Sclerosis in 1995 at the age of 31.
- I love my life, but I have always been a fiercely independent woman, and I want to have choice about how and when I die. Should living become unbearable to me, I want to be able to ask for, and receive help to die with dignity.
- British law does not allow this, and makes assisting someone to die a crime punishable by up to 14 years in prison, so my options are to attempt suicide myself, and risk making matters worse, or to travel to Switzerland to have an assisted death.
- My husband knows that if he was able to help me collect the necessary paperwork and make travel arrangements, I could delay making this decision, maybe forever, and for this reason he is prepared to risk a prison sentence. But I do not want Omar or any other person dear to me to be made a criminal for what I see as an act of love and humanity.
- I will go overseas to die, alone and unaided, while I still can, if that is the only way I can be in control of my death and protect my husband. But it should not have to be this way. The law in the UK is forcing me to consider dying before I am ready. It should be changed so that me, and others like me, can know that if our suffering does become unbearable we can choose an assisted death.